DOCUMENT RESUME

ED 416 648 EC 306 207

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TITLE HIV/AIDS and Pediatric AIDS. The Arc Q & A.
INSTITUTION Arc, Arlington, TX.
PUB DATE 1997-11-00
NOTE 4p.
AVAILABLE FROM Arc National Headquarters, 500 E. Border St., S-300, Arlington, TX 76010; phone: 817-261-6003; TDD: 817-277-0553.
PUB TYPE Guides - Non-Classroom (055) -- Information Analyses (070)
EDRS PRICE EDRS Price MF01 Plus Postage. PC Not Available from EDRS.
DESCRIPTORS *Acquired Immune Deficiency Syndrome; Children; *Communicable Diseases; Disease Control; Elementary Secondary Education; Incidence; Infants; *Pediatrics; Preschool Education; Special Health Problems; *Symptoms (Individual Disorders)

ABSTRACT

This fact sheet uses a question-and-answer format to summarize what is known about HIV/AIDS (Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome) and pediatric AIDS and applies this information to children in school settings. Questions and answers address the following topics: what the AIDS disease and HIV infection are; estimates of the number of children infected with HIV; ways that children become infected with the HIV virus; testing of children for the presence of the HIV antibody; the use of drugs to treat children with AIDS; the neurological and developmental effects of AIDS and HIV in children; services that might be needed in the school setting for the HIV-infected child; who should know that a child in school has AIDS or is HIV-positive; and precautions that should be taken to prevent exposure to HIV by school-aged children. (DB)

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Q&A

HIV/AIDS and Pediatric AIDS

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What is AIDS?

AIDS stands for Acquired Immune Deficiency Syndrome. It is a disease caused by the Human Immunodeficiency Virus (HIV), sometimes referred to as the AIDS virus. A person who is infected with the HIV virus is considered HIV positive. This virus attacks the T-cells, which are part of the body's immune system. The loss of T-cells prohibits the body from fighting off bacteria that it is normally able to destroy before they cause disease. The type of diseases that HIV infection causes are commonly referred to as opportunistic infections.

How many children are infected with HIV in the United States?

The latest estimated number of HIV-infected children living in the U.S. is more than 12,000, with nearly 40 percent of those of school age. More than 1,600 HIV-infected children were born in 1993 alone, and these children have a life expectancy of more than nine years. Since they are likely to be attending school, the children, their parents and the schools must deal with HIV. Of those in public school, attendance varied, but most had relatively few absences. Half of the group missed less than two weeks of the school year. In one study done in Massachusetts, of 92 school-aged children with HIV, only three were too ill to attend school, five were home-schooled and the other 84 attended school outside the home.

How are children infected with the HIV virus?

Prior to 1996, children were infected from their undiagnosed mothers before being born, during the birthing process or after birth through breast feeding. Since then, the Centers for Disease Control and Prevention (CDC) has strongly recommended that all pregnant women be tested for the presence of the HIV antibody. For those HIV-positive pregnant women, the use of AZT is the standard protocol to prevent the virus from being passed to their unborn child. It is recommended that a woman be given AZT during the second trimester of her pregnancy and during the birthing process. While AZT is not 100 percent effective in preventing the transmission of HIV to the unborn child, the outcome for children whose mothers receive treatment is much better.

Most cases of pediatric AIDS occur in children with coagulation disorders, like hemophilia, when they are infected with HIV through blood products. The treatment of their bleeding disorder requires the pooling of blood products for transfusion. This means that one transfusion of clotting factor may expose the children to the blood products of 300-400 persons. The number of events multiplied by the number of transfusions times the potential exposures results in a high probability that the children could be exposed to HIV. It is easy to understand why so many children with hemophilia are HIV-positive.

When should children be tested for the presence of the HIV-antibody?

Any child born to an HIV-positive mother should be tested at regular intervals of about every three months up to the age of 18-24 months to determine the child's HIV status. If a child was treated with AZT before birth, close monitoring to detect side effects is recommended until the age 21. If a child is born to a known HIV-negative mother and the child does not have any unusual health problems, there is no need to consider regular testing for the HIV antibody.

Most undiagnosed children with HIV develop health problems that may not be difficult or unusual, but they fail to improve and attain good health in the same time period as an HIV-negative child with a similar problem. When this is the case, the child should be evaluated for an underlying medical problem.

In the case of children with hemophilia, testing for the presence of the HIV antibody should be performed regularly as determined by the doctor.

How are drugs used to treat children with AIDS?

It is extremely important to emphasize that ALL pediatric AIDS patients must be followed by a physician with the experience and expertise to manage these complicated patients. Also the drug regimes, dosages and monitoring for side effects must be followed closely because the recommendations change quickly.

The current recommendations for drug therapies in children with AIDS are very complicated. The choice of drugs and combinations of drugs is dependent on different laboratory tests and how well the child is feeling. Also, these children need to be followed closely for the development of any opportunistic diseases such as thrush, skin cancers, and pneumonia. If these diseases develop, then other medications will need to be added.

Another important point to remember for children with AIDS is that when the time comes for their routine vaccinations, it is now recommended that these children not receive immunizations with "live" viruses, as these may precipitate the disease.

What are the neurological and developmental effects of AIDS and HIV in children?

Before addressing the actual effects of the virus on the child, it is important to mention some of the underlying problems of these children. First, many of these children are born to mothers who have a history of substance abuse. This fact is an important contributor in the development of neurological problems in any child. Second, in those children with hemophilia, there may be a history of head trauma and

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decreased oxygen flow to the brain that may cause neurological problems. Third, there is no doubt that HIV is found more often in the poorer population. This fact may prevent a woman from obtaining prenatal care and maintaining an adequate diet to prevent any type of neurological problem. The effects of any of these problems would be compounded by the problem of HIV/AIDS, the effects of drugs used to treat HIV, and the effects of high levels of virus in the blood of the developing child.

The frequency of problems with nervous system development in children with HIV is between 78-93 percent. The types of problems identified included deficits in motor performance, thinking skills, communication, social, and behavioral areas, plus a variety of abnormal development patterns. The range of neurological findings in children with HIV infection include developmental delays, difficulty walking, some movement disorders, small head size, and difficulties with sensations.

Studies have revealed that 65 percent of the children with nervous system involvement from HIV lose functioning quickly. About a quarter of the patients have a more stable neurological picture, and about 10 percent have no gross neurological dysfunction, at least during the study period. Although some patients had a rapid downhill course, most had a slower progressive course. With this second group, many reached periods in their development where they remained in fairly good health for months or years. Although this is true for their general health and their developmental functioning, both of these areas are related to the rate of their HIV progression. That is to say that if the HIV/AIDS is controlled, then overall functioning seems to be fairly stable.

In one group of clinically stable children with apparently normal development, there was a high rate of vision problems that included not only their ability to see, but also their ability to interpret what they saw and the coordination of movement with their visual perceptions. However, this same group did not appear to have problems with language.

There is still no one answer about the cause of developmental and neurological problems in children with HIV/AIDS. Some research has suggested that the HIV virus itself affects the brain by shrinking it or by the release of toxic wastes that cause a reaction in the brain that destroys nerve cells. Another explanation is that the same type of opportunistic infections that occur elsewhere in body systems also happen in the brain. A variety of other effects have been noted in the nervous system and brains of HIV infected persons that may explain these problems.

What services might be needed in the school setting for the HIV-infected child?

Some children with AIDS will need more services than others. The first question is whether the child will need special education services. Additional services that may be needed include hearing aides, glasses, language/speech therapies or devices, or respiratory devices. Participation in sports and extracurricular activities needs to be addressed because of the potential exposure of other students to the body fluids of the infected person. Teenagers who are HIV-positive should have specific instructions about the need to protect their sexual partners from HIV infection.

Who should know that a child in the school has AIDS or is HIV-Positive?

This remains a very controversial area of law and ethics. Every state legislature has established specific rules and regulations that guide the interpretation of these laws with regards to "need to know." These laws are not universal, so each person needs to know what his state says about who needs to know and under what circumstances. Unlike other diseases, parents of children with AIDS often feel morally challenged about who to tell and what to do. Parents must not only decide who to tell, but whether to allow the child to go to school in the first place. It is important to remember that the child with AIDS is in a compromised immune status, and her life is potentially threatened by another child with a cold or strep throat.

There is no simple answer to this question, but every family needs to make this decision for themselves with guidance from a caring health care team.

What precautions should be taken to prevent any school-aged child from exposure to HIV?

Generally, everyone must have knowledge of what is meant by and how to implement universal precautions. Barrier protection, personal cleanliness, and disinfection are the keys to universal precautions. Barrier protection places a shield between another person's body fluids and you (i.e., wearing gloves to clean up blood). Personal cleanliness is a matter of consistent and careful cleanliness in the workplace and at home. Disinfection is the act of removing germs from equipment, instruments and surfaces that may have come in contact with body fluids. The key element in the application of universal precautions is to treat every person as if he is already infected. An important lesson to teach all children is when there is blood involved, they should get an adult to take care of the problem.

As children become older, other age-appropriate information should be added. It is important to emphasize that no matter what the underlying problem or condition is, all persons need and deserve to be treated with care and compassion.

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England, JA et al. Zidovudine, didanosine, or both as the initial treatment for symptomatic HIV-infected children. N Engl J Med. 1997 Jun 12; 336: 1704-12.

Resources:

National AIDS Clearinghouse, 1-800-485-5231
1-800-243-7012 (TDD)

National Association of People With AIDS (NAPWA)
202-898-0414

American Red Cross, 703-206-7180

Contact The Arc for HIV and mental retardation materials:
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#101-59 Nov. 1997

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